Bioethics for clinicians: 6. Advance care planning

Peter A. Singer, MD, MPH, FRCPC; Gerald Robertson, LLB, LLM; David J. Roy, STL, PhL, DrTheol

Abstract • Résumé

Advance care planning is a process whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care. Grounded in the ethical principle of autonomy and the legal doctrine of consent, advance care planning helps to ensure that the norm of consent is respected should the patient become incapable of participating in treatment decisions. Physicians can play an important role by informing patients about advance care planning directing them to appropriate resources, counselling them as they engage in advance care planning and helping them to tailor advance directives to their prognosis.

La planification des soins est un processus dans le cadre duquel un patient, en consultation avec des fournisseurs de soins de santé, des membres de sa famille et d'autres personnes importantes, prend des décisions sur ses soins de santé à venir. Fondée sur les principes éthiques de l'autonomie et sur la doctrine légale du consentement, la planification des soins aide à assurer que l'on respectera la norme du consentement si le patient devient incapable de participer à la prise de décisions relatives au traitement. Les médecins peuvent jouer un rôle important en informant les patients au sujet de la planification des soins, en les orientant vers les ressources appropriées, en les conseillant au moment où ils entreprennent la planification des soins et en les aidant à formuler des directives préalables en fonction de leur pronostic.

Mrs. Q is 63 years old and has no significant history of illness. She presents for a routine visit to her family physician. She recently read a newspaper article about a new law on living wills and wants to obtain some advice about them.

Mr. R is a 40-year-old man who was diagnosed 2 years ago with HIV infection. He presents to an internist with symptoms of early dementia. The internist considers what Mr. R. should be told about advance directives.

What is advance care planning?

Advance care planning is a process whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care.[1] This planning may involve the preparation of a written advance directive.[2,3] Completed by the patient when he or she is capable, the advance directive is invoked in the event that the patient becomes incapable. (The question of capacity is discussed in the

Dr. Singer is Director of the University of Toronto Joint Centre for Bioethics, Associate Professor of Medicine at the University of Toronto, and Staff Physician with The Toronto Hospital, Toronto, Ont. Mr. Robertson is Professor of Law at the University of Alberta, Edmonton, Alta. Dr. Roy is Director of the Centre for Bioethics, Clinical Research Institute of Montreal, Research Professor at the Faculty of Medicine, Université de Montréal, and Director and Coordinator of the Quebec Research Network in Clinical Ethics, Fonds de la recherche en santé du Québec, Montreal, Que.

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Correspondence to: *Dr. Peter A. Singer (series editor), University of Toronto Joint Centre for Bioethics, 88 College St., Toronto ON M5G 1L4; fax 416 978-1911; peter.singer@utoronto.ca*

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third article in this series [see sidebar].) Advance directives indicate whom the patient would want to make treatment decisions on his or her behalf and what interventions the patient would or would not want in various situations.

Why is advance care planning important?

Ethics

Advance care planning helps to ensure that the norm of consent is respected when sick people are no longer able to discuss their treatment options with physicians and thereby exercise control over the course of their care. This norm is grounded in the principle of self-determination and respect for autonomy, a classic expression of which is Justice Benjamin Cardozo's statement in 1914 that "Every human being of adult years and sound mind has the right to determine what shall be done with his own body."[4]

Although the principle of self-determination places high value on individual liberty, the usefulness of advance care planning is not limited to those whose world-view valorizes individualism. Advance care planning also rests on the principle of respect for persons, and this respect must extend to those whose cultural values emphasize the interdependence of human beings and the well-being of the family or community as a whole. Advance care planning recognizes that sick people suffer a loss of dignity when they cannot command respect for their considered and cherished intentions and that such intentions may be shaped by cultural values.

Advance care planning cannot avert all ethical uncertainties and conflicts in clinical decision-making. Some patients change their views as time passes, and others request life-prolonging interventions that subsequently prove to be unrealistic. Moreover, substitute decision-makers are not always sure that a patient's situation is equivalent to that described in an advance directive.

Law

British Columbia,[5] Alberta,[6] Manitoba,[7] Ontario,[8,9] Quebec,[10] Nova Scotia,[11] Prince Edward Island[12] and Newfoundland[13] have legislation supporting the use of advance directives. (In British Columbia, Alberta and Prince Edward Island, this law has not yet been proclaimed.) An advance directive is referred to in law by various names: "representation agreement" (British Columbia), "personal directive" (Alberta), "health care directive" (Manitoba), "power of attorney for personal care" (Ontario), "mandate given in anticipation of . . . incapacity" (Quebec), "consent agreement" (Nova Scotia) and "advance health care directive" (Newfoundland). The legislation varies from province to province with respect to the scope of advance directives, who can act as proxy for the patient, requirements for witnessing the advance directive, procedures for activating the advance directive, and so on. Physicians should familiarize themselves with the legislation in their province or territory. Even when there is no legislation, legal decisions such as that made in *Malette* v. *Shulman* and other cases[14,15] suggest that advance directives may still be legally valid.

Policy

The CMA supports the use of advance directives,[16] and some hospitals and long-term care facilities have policies regarding advance directives.[17,18]

Empirical studies

Key findings from empirical studies can be summarized as follows.

- Advance directives are generally viewed in a positive light by physicians and patients.[19–29] For example, 85% of family physicians in Ontario favoured the use of advance directives,[30] and 62% of medical outpatients wanted to discuss their preferences with regard to life-sustaining treatment.[31]
- Only 12% of Ontarians and 10% of Canadians have completed an advance directive form.[32,33]
- People change their preferences over time with respect to life-sustaining treatment.[34,35]
- Cultural values play an important role in advance care planning.[36,37]
- The implementation of programs to encourage advance care planning is associated with increased use of advance directives.[38–47]
- Few studies have been done on substitute decision-making for incapable persons with or without advance care plans and advance directives.[48,49]
- The effect of advance directives on health care costs has been the subject of debate.[50–54] Findings from the largest and most recent randomized trial do not support the hypothesis that the use of advance directives decreases health care utilization or costs.[55]

How should I approach advance care planning in practice?

The previous article in this series addressed the role of advance directives in substitute decision-making for incapable patients [see sidebar]. In this article we focus on the process of planning care with capable patients.

The main goal of advance care planning is "to ensure that clinical care is shaped by the patient's preferences when the patient is unable to participate in decision making."[56] Moreover, it has recently been recognized that such planning is a social process that requires communication among all concerned; it is not simply the act of completing an advance directive form.[1,57]

The role of the physician in advance care planning is

still being defined. Some authors believe that the physician's role is central. For example, Emanuel and associates[57] describe a framework for advance care planning within the context of the physician–patient relationship. This conception does not take into account the fact that many Canadians complete advance directives with the assistance of a lawyer in the context of estate counselling, or that over 2 million people requested Power of Attorney for Personal Care forms from the Office of the Public Guardian and Trustee after the Substitute Decisions Act was passed in Ontario. A broader view of advance care planning suggests that it occurs outside the context of the physician–patient relationship. Some preliminary research findings support this view.[58]

Understanding advance care planning in a broader social context calls for a re-evaluation of the part that physicians and other health care providers have to play. If advance care planning occurs within families, for example, the physician should support that planning rather than direct it. The physician's primary role is that of educator. Physicians who raise the issue of advance care planning with patients who are unaware of their rights with respect to advance directives perform a valuable service. Patients who request assistance with advance care planning should first be directed to relevant information sources; these include documents provided by provincial governments, self-help publications such as *Let Me Decide*[59] and the *Living Will* booklet and video available through the University of Toronto Joint Centre for Bioethics.

Once a patient has obtained general information about advance care planning, the physician can help him or her to tailor an advance directive to the particular health situation of concern. Compared with the "generic" approach of preprinted advance directive forms, a "disease-specific" approach is less hypothetical and can be based on more precise prognostic information.[60] For instance, a physician caring for a patient with severe chronic obstructive pulmonary disease could draw the patient's attention to the issue of intubation and ventilation in the event of respiratory failure.

The physician can also ensure that the patient has correctly interpreted the information contained in a preprinted advance directive and is capable of completing it.[61,62]

Lawyers can make an important contribution by ensuring that an advance directive conforms to provincial legislation and is consistent with the patient's overall planning with regard to future incapacity and death. (This may involve other matters such as designating power of attorney for finances and preparing an estate will.)

Research conducted at the University of Toronto Joint Centre for Bioethics has found that counselling is a valuable component of advance care planning. Whether such counselling is best performed by a physician, lawyer, nurse, social worker or other educator is unknown.

Physicians should suggest that patients review their advance care plans when their health status changes. This will help to ensure that the patient's preferences as expressed in an advance directive are current and likely to apply to future treatment decisions.

When the patient becomes incapable and his or her advance directive takes effect, the physician will seek consent to proceed with the proposed treatment plan from the substitute decision-maker appointed in the advance directive, as discussed in the previous article in this series [see sidebar].

Cases revisited

Mrs. Q is requesting information about advance care planning. Her physician should refer her to one of the available information sources and encourage her to begin the process of advance care planning with her preferred substitute decision-maker. After a period of time, Mrs. Q and her substitute might together meet with the physician. At this meeting, the physician can review Mrs. Q's treatment preferences to ensure that she has understood the information in the advance directive form and is capable of completing it. If Mrs. Q is concerned about the legal validity of her advance directive, the physician might recommend that she consult a lawyer. If her health situation changes, the physician should recommend that Mrs. Q update her advance directive.

Mr. R, unfortunately, may soon be incapable of making health care decisions. The physician should raise the subject of advance care planning with him in a sensitive manner and follow the same steps as described for Mrs. Q. However, in the case of Mr. R, the physician will have to pay particular attention to the issue of capacity. This situation also represents an opportunity for the physician to tailor the information considered by Mr. R in advance care planning to the likely future: progressive cognitive deterioration.

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Next month: Truth telling

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